ORIGINAL ARTICLES

Limited Literacy and Mortality in the Elderly

The Health, Aging, and Body Composition Study

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BACKGROUND: While limited literacy is common and its prevalence increases with age, no prospective study has assessed whether limited literacy is associated with mortality in older adults.

OBJECTIVE: To assess the association of limited literacy with mortality.

DESIGN AND SETTING: Five-year prospective study from 1999 to 2004 of community-dwelling elders from Memphis, TN, and Pittsburgh, PA, who were from the Health, Aging, and Body Composition study. Subjects' literacy was assessed with the Rapid Estimate of Adult Literacy in Medicine. Scores were categorized into limited (0 to 8th grade reading level) or adequate literacy ($\geq$ 9th grade reading level).

PARTICIPANTS: Two thousand five hundred and twelve black and white elders without baseline functional difficulties or dementia.

MEASUREMENTS: Time to death.

RESULTS: Participants' mean age was 75.6 years, 48% were male, 38% were black, and 24% had limited literacy; the median follow-up time was 4.2 years. Compared with those with adequate literacy, those with limited literacy had a higher risk of death (19.7% vs 10.6%) with a hazard ratio (HR) of 2.03 (95% confidence intervals [CI], 1.62 to 2.55). After adjusting for demographics and socioeconomic status, co-morbid conditions, self-rated health status, health-related behaviors, health care access measures, and psychosocial status, limited literacy remained independently associated with mortality (HR 1.75; 95% CI, 1.27 to 2.41).

CONCLUSIONS: Limited literacy is independently associated with a nearly 2-fold increase in mortality in the elderly. Given the growth of the aging population and the prevalence of chronic diseases, the mechanisms by which limited literacy is associated with mortality in the elderly warrant further investigation.

KEY WORDS: educational status; mortality; aged; literacy; health status.
DOI: 10.1111/j.1525-1497.2006.00539.x
J GEN INTERN MED 2006; 21:806–812.

An estimated 90 million American adults have limited literacy, and limited literacy is associated with being poor, having lower educational attainment, and being a member of a racial or ethnic minority group.[1] In addition, approximately half of adults over age 60 scored in the lowest reading level and this percentage increased with age.[1] A recent review found that the pooled prevalence of limited literacy within the health care setting was 38% in adults aged 50 or older[2]; however, it has been reported to be as high as 81% among elders from a public hospital.[3]

Given the disproportionate chronic disease burden among elders, those with limited literacy may be particularly at risk for poor health outcomes. Patients with limited literacy are more likely to have a poor understanding of their chronic disease, worse disease self-management, worse self-rated health, and a higher likelihood of hospitalization.[3–9] However, most literacy studies have been limited by their cross-sectional design. Although lower educational attainment has been associated with mortality,[10–12] no studies have explored whether limited literacy is associated with mortality.

Our objective was to assess the relationship between limited literacy and mortality in a prospective cohort of racially diverse, community-dwelling elders. As the elderly population grows and the burden of chronic diseases increases,[13] our findings could have important public health implications for health communication and health care delivery.

METHODS

Study Population

Study participants were part of the ongoing, prospective Health, Aging, and Body Composition (Health ABC) study begun in 1997, which recruited 3,075 Medicare-eligible community-dwelling men and women aged 70 to 79 years. Participants were identified from a random sample of white, Medicare beneficiaries and all age-eligible black residents in designated ZIP code areas surrounding the 2 field centers, the University of Pittsburgh, and the University of Tennessee, Memphis. Details of the sampling procedures have been described previously.[14] Residents in designated ZIP code areas were mailed brochures, and participation was encouraged through community-based activities. All eligible residents were then contacted by phone to request participation and to assess their functional status, with additional recruitment efforts targeted to black participants. Participants were well functioning at baseline, as exclusion criteria included any self-reported difficulty walking one-quarter of a mile, climbing a

The results of this study were presented at the 28th Annual Society of General Internal Medicine Meeting, May, 2005.

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flight of stairs, performing basic activities of daily living, clinical dementia,[15] or inability to communicate with the interviewer. Literacy was assessed in study year 3. Of the original 3,075 participants, literacy was not assessed in 563 subjects due to: death ($n=107$); withdrawal from the study ($n=6$); poor eyesight (self-reported inability to see large print even with the help of corrective or magnifying lenses) ($n=14$); refusal ($n=13$); lack of an in-person clinic interview ($n=418$); and missing data ($n=5$), leaving 2,512 participants. This study was approved by the institutional review boards of the University of California, San Francisco, the University of Tennessee, and the University of Pittsburgh.

Literacy Assessment

Literacy was assessed during year 3 of the Health ABC Study (1999) using the Rapid Estimate of Adult Literacy in Medicine (REALM), which has been correlated with other standardized tests of literacy.[16,17] The REALM is a word recognition and pronunciation test with scoring based on correct pronunciation of 66 common medical terms.[16] Uniform administration and scoring of the REALM was achieved by standardized training and direct observation of a subset of test administrations. The REALM scores of 0 to 18, out of a possible 66, represent a reading level of 3rd grade or less ("may not be able to read most low-literacy materials and may need repeated oral instructions"); scores of 19 to 44 represent a 4th to 6th-grade reading level ("may need low-literacy materials and may not be able to read prescription instructions"); scores of 45 to 60 represent a 7th to 8th-grade reading level ("may struggle with most currently available patient education materials"); and scores greater than 60 represent a 9th-grade reading level or above ("should be able to read most patient education materials").[16] By convention, participants scoring less than the 9th grade were considered to have limited literacy and those scoring at the ninth grade or higher were considered to have adequate literacy.[16] The 0 to 3rd and 4th to 6th-grade reading levels were combined into a 0 to 6th category due to the small sample size in the lowest reading group ($n=58$).

Correlates of Literacy

Only demographic and socioeconomic characteristics, including age, self-reported race, gender, yearly family income ($\geq$\$50K, \$25K to $<$50K, \$10K to $<$25K, $<$\$10K), and education (postgraduate, college, vocational training or some college, high school, $<$high school), were measured at year 1 of the Health ABC Study (1997). All other variables were measured at year 3 (1999), including the following chronic conditions: cardiac disease, stroke, hypertension, diabetes, cancer (all by using a combination of self-reported physician diagnosis, clinical data obtained at yearly study examinations, and medication use), and obesity determined by a body mass index $>30\,kg/m^2$. At year 3, we also assessed self-rated health (excellent, very good, good, fair, poor); health-related behaviors, including smoking (current or former smoker), and 1 or more alcoholic drinks per day; and access to health care, including whether they had a regular doctor or regular place of care, had obtained a flu shot in the prior 12 months, or had supplemental insurance that covered medications. Year 3 psychosocial measures included high depressive symptoms, defined as a score ≥ 16 out of 60 on the Center for Epidemiologic Study Depression Scale (CES-D)[18]; poor personal mastery, defined as either lack of confidence to accomplish tasks or feeling helpless in dealing with life's problems[19]; and living alone. We also assessed incident cognitive impairment defined, by convention, as a decline of greater than 5 points on the 100-point Modified Mini-Mental State Exam (3MS)[20,21] from year 1 (before the literacy evaluation) to year 5 (when the most recent 3MS was administered).

Outcome: Mortality

All-cause mortality data were collected from July 1999 (year 3, at the time of the literacy assessment) to August 2004. Death events and cause of death were adjudicated by committee.[22] Information used to identify death events included notification of death during any attempt to contact participants; the notification of death to Health ABC field centers by proxy, spouse, relative, or friend; hospital record review; review of local newspaper obituaries; and Social Security Death Index data. All death events were subsequently confirmed with death certificates. Underlying cause of death was identified using hospitalization records.

Statistical Analyses

The association of limited literacy with demographic characteristics, self-rated health and co-morbidities, health-related behaviors, health care access and psychosocial status correlates, and cause of death was assessed by comparing means and percentages using t tests or the χ^2 test by literacy level (limited vs adequate literacy).

For the all-cause mortality analyses, the censor date was the reported date of death and/or the documented date of last contact with the participant. At the time of committee adjudication of death events, participants who did not have data for the last clinic visit but were not adjudicated as dead were assumed to be alive. We calculated Kaplan-Meier survival curves, and used Cox proportional hazard modeling in which literacy levels were divided into limited and adequate (referent group). In multivariable analyses, we created separate models partially adjusting for variables within the following categories: demographics, health status, health-related behavior, health care access, and psychosocial status. We then created a fully adjusted model with all the aforementioned variables. Variables were included in the models if they were associated with mortality or literacy at $P\leq.1$ in bivariate analyses.

To evaluate the interrelation of race, gender, education, and income with limited literacy and mortality, we performed subgroup analyses to determine the proportion of elders who died among each demographic group. Education and income were dichotomized into $\geq$ or $<$ high school and $\geq$ or $<$\$10K to ensure adequate sample size in each subgroup. Interactions between limited literacy and demographic variables associated with mortality were assessed in the multivariable models; an interaction term P value $\leq.1$ was considered statistically significant.

We also derived a propensity score from a logistic model that included age, race, gender, income, and education, using limited literacy as the outcome.[23] Each participant who had limited literacy was matched to a unique control with adequate literacy, but who had a similar propensity score for limited literacy based on demographic characteristics. Cox proportional

hazard modeling was repeated using the adjustments from the derived propensity scores.

Given the relationship between cognitive test performance and literacy level observed in previous studies[24,25] and in this cohort (Pearson's correlation coefficient =0.63), we performed a sensitivity analysis by excluding participants who developed incident cognitive impairment.

We assessed the proportional hazard assumptions of the Cox regression models using the Schoenfeld test.[26] All analyses were conducted using Intercooled Stata, version 8 software.[27]

RESULTS

Among 2,512 participants with a literacy assessment at year 3, 23.7% (n=595) had limited literacy. The mean age of the cohort was 76 years, with a range of 71 to 82 years. Forty-eight percent of the cohort was male, 38.1% was black, 22.1% did not complete high school, and 11.9% had annual family incomes less than $10,000 (Table 1).

Participants with limited literacy, when compared with participants with adequate literacy, were more likely to be male, black, have less education, and lower incomes (all $P<.001$, Table 1). The mean age did not vary with literacy level. A higher proportion of participants with limited literacy reported having "fair" to "poor" health, and had hypertension, diabetes, obesity, high depressive symptoms, poor health-related behaviors, poor access to health care, and poor psychosocial status (all $P<.05$, except for living alone). All variables except for income, obesity, health care access variables, and living alone also were associated with mortality ($P<.05$).

The mean follow-up from year 3 (1999) onward was 5.1 years (median 4.2 years). During follow-up, 320 (12.7%) participants died. The percentage of deaths was higher in the limited literacy (19.7%) compared with the adequate literacy group (10.6%, $P<.001$, Fig. 1). Compared with elders with adequate literacy, those with limited literacy had higher all-cause mortality (hazard ratio [HR] 2.03; 95% confidence interval [CI], 1.62 to 2.55; Table 2). The association of limited literacy

Table 1. Demographic and Health-Related Characteristics of Participants by Literacy Level*

	Overall (n=2,512)	0 to 8th grade (n=595)	≥9th Grade (n=1,917)	P value†
Demographics	Percentage or mean ± SD			
Age	75.6 ± (2.8)	75.7 ± (2.9)	75.6 ± (2.8)	.364
Gender: male	48.0	57.0	45.2	<.001
Race: black	38.1	72.1	27.5	<.001
Education				
Postgraduate	12.9	1.9	16.2	<.001
College	13.1	3.7	16.3	
Vocational/some coll	23.9	11.5	27.7	
High school	27.8	24.1	29.0	
<High school	22.1	58.8	10.8	
Income				
≥$50K	17.5	5.5	21.1	<.001
$25K to <$50K	33.3	18.7	37.7	
$10K to <$25K	37.4	47.5	34.5	
<$10K	11.9	28.4	6.8	
Health status and chronic disease				
Self-rated health				
Excellent	11.5	8.4	12.5	<.001
Very good	33.2	26.9	35.2	
Good	37.5	35.0	38.3	
Fair	15.6	33.6	12.5	
Poor	2.0	4.0	1.4	
Cardiac disease	20.7	21.5	20.5	.6
Stroke	8.6	8.1	8.8	.6
Cancer	7.6	7.1	7.8	.5
Hypertension	56.6	62.7	54.7	<.001
Diabetes	17.1	25.2	14.6	<.001
Obesity‡	24.9	31.1	23.0	<.001
Health-related behaviors				
Current smoker	9.0	13.8	7.5	<.001
Former smoker	46.0	42.4	47.1	.048
1 alcoholic drink/day	7.4	4.4	8.4	.001
Poor health care access				
Lack primary doctor or clinic	5.3	7.2	4.8	.019
Lack flu shot past 12 mo	22.1	31.2	19.2	<.001
Lack insurance for medications	36.0	45.4	33.1	<.001
Poor psychosocial status				
High depressive symptoms§	2.1	3.9	1.6	.001
Poor personal mastery‖	22.9	27.6	21.4	.002
Lives alone	30.3	29.2	30.6	.539

Literacy level based on Rapid Estimate of Adult Literacy in Medicine (REALM) score: 0 to 60=0 to 8th-grade reading level (limited literacy) and 61 to 66=9th-grade reading level (adequate literacy).

†P *value, t test for continuous variables and* χ^2 *for dichotomous variables, comparing 0 to 8th-grade and* ≥ *9th-grade reading levels.*

‡*Body mass index* >30 kg/m^2.

§*High depressive symptoms defined as* ≥ *16 on the Center for Epidemiology Study Depression Scale.*

‖*Poor personal mastery: lacks confidence accomplishing tasks or feels helpless dealing with life's problems.*

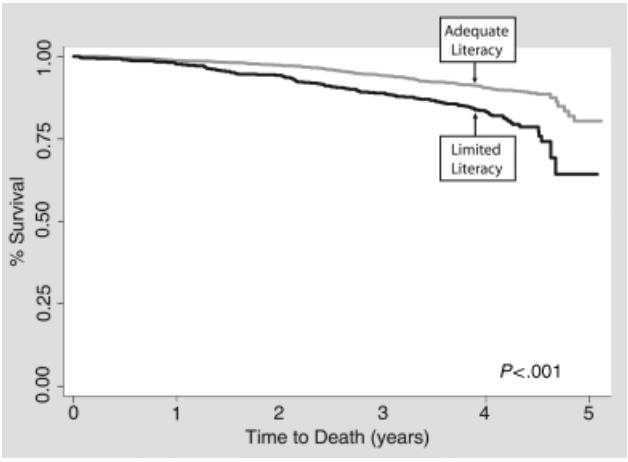

FIGURE 1. All-cause mortality by literacy level. Adequate literacy (upper line) is defined by a Rapid Estimate of Adult Literacy in Medicine (REALM) score consistent with ≥9th grade reading level. Limited literacy (lower line) is defined by a REALM score consistent with 0 to eighth grade reading level.

with mortality persisted after adjusting for demographic and socioeconomic characteristics, co-morbidities and self-rated health status, health-related behaviors, health care access, and poor psychosocial status (HR 1.75; 95% CI, 1.27 to 2.41). The only predictors in the model with a stronger association with mortality were poor self-rated health (HR 2.17; 95% CI, 0.99 to 4.71) and being a current smoker (HR 3.09; 95% CI, 2.11 to 4.53; Table 3).

To assess dose-response or threshold effects, we assessed the risk of death after dividing literacy levels into 0 to 6th (n=117) and 7th to 8th (n=203), with the ≥9th-grade reading level as the referent group. When compared with ≥9th-grade level, both the 0 to 6th and the 7th to 8th reading levels had approximately the same adjusted risk of death (HR 1.82; 95% CI, 1.08 to 2.05 and 1.63; 95% CI, 1.16 to 2.31, respectively).

Table 2. Association of Limited Literacy with Mortality

Cox Proportional Hazard Models	Mortality Hazard Ratio (HR) and 95% Confidence Intervals (CI) n=2,512
Unadjusted	2.03 (1.62 to 2.55)
Partial adjustment	
Demographics*	1.83 (1.34 to 2.50)
Health status†	1.86 (1.47 to 2.35)
Heath related behaviors‡	2.12 (1.69 to 2.67)
Poor health care access§	2.01 (1.59 to 2.55)
Poor psychosocial status‖	1.96 (1.56 to 2.47)
Fully adjusted	1.75 (1.27 to 2.41)

*Demographics: age, race, gender, income, education.
†Health status: self-rated health, cardiac disease, stroke, cancer, hypertension, diabetes, obesity.
‡Health-related behaviors: Either former smoker (>100 cigarettes in lifetime) or current smoker. Drinking>1 alcoholic beverage per day.
§Poor health care access: lack of a regular doctor or clinic, no flu shot within the past 12 months, no insurance to cover medications.
‖Psychosocial status: high depressive symptoms, poor personal mastery.

Table 3. Association of Each Variable in the Fully Adjusted Cox Model with Mortality

Variables	Mortality Hazard Ratio (HR) and 95% Confidence Intervals (CI)
Limited literacy	1.75 (1.27 to 2.41)
Demographics	
Age	1.10 (1.05 to 1.14)
Gender: male	1.29 (0.97 to 1.71)
Race: black	1.07 (0.79 to 1.44)
Education (reference: postgraduate)	
College	0.70 (0.43 to 1.15)
Vocational training/some college	0.73 (0.47 to 1.14)
High school	0.81 (0.52 to 1.25)
<High school	0.66 (0.40 to 1.08)
Income (reference ≥ $50K)	
$25K-<$50K	1.13 (0.77 to 1.66)
$10K-<$25K	0.88 (0.57 to 1.35)
<$10K	1.04 (0.60 to 1.80)
Health status	
Self-rated health (reference: excellent)	
Very good	1.10 (0.68 to 1.78)
Good	1.36 (0.85 to 2.17)
Fair	1.59 (0.95 to 2.67)
Poor	2.17 (0.99 to 4.72)
Cardiac disease	1.40 (1.07 to 1.83)
Stroke	1.30 (0.88 to 1.85)
Cancer	1.67 (1.14 to 2.46)
Hypertension	1.21 (0.93 to 1.58)
Diabetes	1.52 (1.14 to 2.04)
Obesity	0.83 (0.61 to 1.12)
Health-related behaviors	
Current smoker	3.09 (2.11 to 4.53)
Former smoker	1.70 (1.26 to 2.29)
≥1 alcoholic drink/day	1.49 (1.00 to 2.20)
Poor health care access	
Lack primary doctor or clinic	1.12 (0.66 to 1.91)
Lack flu shot past 12 mo	1.16 (0.86 to 1.58)
Lack insurance for medications	0.98 (0.75 to 1.27)
Poor psychosocial status	
High depressive symptoms	0.67 (0.29 to 1.54)
Poor personal mastery	1.15 (0.87 to 1.53)

We estimated the hazard of death between pairs matched on propensity score for limited literacy, based on demographic characteristics. The propensity score ranged from 0.036 to 0.902, with a strong concordance index of 0.846. Four hundred and twelve participants with limited literacy were matched with 412 unique control participants with adequate literacy. The adjusted hazard of death remained significant and of similar magnitude (HR 1.68; 95% CI, 1.18 to 2.39).

We observed similar patterns within the 4 subgroups (gender, race, income, education), with limited literacy participants in each subgroup having higher mortality (Table 4). None of the interactions were statistically significant (P>.10).

From year 1 to year 5, 383 (15.2%) participants had evidence of incident cognitive impairment. An interaction was found between incident cognitive impairment and literacy (interaction term, P=.09). However, excluding participants with incident cognitive impairment did not change the association of limited literacy and mortality (unadjusted HR 2.38; 95% CI, 1.85 to 3.03; adjusted HR 1.94; 95% CI, 1.37 to 2.74).

Information on the underlying cause of death was available or could be adjudicated for 67.2% of decedents. The 3 most common causes were cardiovascular-associated causes

Table 4. Association of Limited Literacy and Mortality Stratified by Demographic Characteristics

Demographic Characteristic	Overall (Number)	Overall Death (%)	0 to 8th Grade* HR (95% CI)
White	1,555	11.1	2.36 (1.63 to 3.42)
Black	957	15.5	1.66 (1.28 to 2.29)
Men	1,206	16.4	2.01 (1.51 to 2.67)
Women	1,306	9.3	1.77 (1.20 to 2.62)
≥ High school education	1,951	11.8	2.27 (1.67 to 3.09)
< High school education	554	15.9	1.77 (1.10 to 2.81)
≥ $10,000 yearly income	2,250	12.4	2.06 (1.60 to 2.64)
< $10,000 yearly income	262	15.7	1.86 (0.96 to 3.60)

* *≥ 9th grade reading level is the referent group.*

(34%), cancer (33%), and cerebrovascular disease (11%). Limited literacy was not associated with any specific underlying cause of death ($P \geq .23$ for all causes).

DISCUSSION

Limited literacy was prevalent in this elderly cohort and was associated with nearly a 2-fold risk of death even after adjusting for demographics and socioeconomic status, co-morbidities and self-rated health, health-related behaviors, access to health care, and psychosocial status. The absolute increased risk of death was 9% over 5 years. The threshold relationship observed, the robustness of the relationship in our propensity matched-pairs analysis, and the results of our sensitivity analyses further strengthen our findings. Consistent with other studies, limited literacy was also associated with the following: socio-demographic characteristics, such as income, education, and race[3,28]; health care access barriers[29]; and common chronic conditions, including hypertension, diabetes, obesity, and poor self-rated health.[5,9,28]

Although illiteracy has been associated with infant and young adult mortality in developing countries,[30,31] no studies have examined the association between limited literacy and mortality in industrialized countries, or in the elderly. Prior studies have examined the association of limited literacy with chronic diseases and health status,[5,7,9,28] receipt of preventive health care,[32,33] increased hospitalizations,[3,7,8,34] and increased health care expenditures[35]; yet, few have assessed outcomes in elderly cohorts.[8,28,32,33] Virtually all studies were limited by their cross-sectional design and none involved community-based samples.

While many adults in industrialized nations have limited literacy skills,[36,37] little is known about explanatory mechanisms for the association between literacy and health. Given the observational nature of our study, we are unable to ascertain the cause of the relationship between literacy and mortality. However, we offer 4 explanatory hypotheses, which may be operating independently or collectively.

First, limited literacy may be an outcome of poorly controlled chronic disease. For instance, diabetes and the metabolic syndrome have been associated with impaired cognition.[38–40] In addition, reading and cognitive activity may prevent cognitive decline,[41,42] and an interaction was present between literacy and incident cognitive impairment in this study. However, excluding participants with incident cognitive impairment during the study period, and adjusting for chronic disease did not alter our findings. Nonetheless, we cannot rule out the possibility that severity of chronic disease over the life course may contribute to limited literacy and poor processing of health information in the absence of a measurable decline in cognition.

Second, the association between limited literacy and mortality may be the result of residual confounding of socioeconomic characteristics of the individual or the community. How low socioeconomic status might lead to higher mortality is not known, although some evidence points to stressful living and working environments, poor social support, worse health-related behaviors, and poor access to health care.[12,43–47] Such socioeconomic factors may have their effects on morbidity and mortality through cumulative physiologic effects across the life span. Although we adjusted for psychosocial and socioeconomic factors in late life, we were unable to account for their combined effects over time.[48,49]

Third, due to the relationship between socioeconomic status and literacy,[3,28,50,51] limited literacy may be a mediator for other variables, such as income, opportunity, social support, and stress on the complex causal path between socioeconomic status and morbidity and mortality. In addition, limited literacy may be an effect modifier, exacerbating the effects of low socioeconomic status on health and health care access.[46,47]

Finally, given the mismatch between the high literacy demands of the health care system and the limited literacy capacities of many older individuals,[50] limited literacy may impede access to health care and/or effective chronic disease management. Health care systems may be poorly designed to meet the needs of persons with limited literacy, thereby contributing to literacy-related disparities. Two trials that evaluated the effect of re-engineering health care delivery to lower literacy demands demonstrated improvements in outcomes among those with lower literacy.[52,53]

This study has a number of limitations. The internal validity of our findings may be affected by selection bias, confounding bias, or measurement error. Although the sample was initially assembled to be representative of well-functioning elders, the additional recruitment efforts needed to obtain a racially diverse cohort may have introduced selection bias. The exclusion of persons with poor physical and cognitive functioning may explain the lower prevalence of limited literacy in the elderly than that previously reported.[28] We cannot rule out confounding by unmeasured characteristics such as the amount and severity of chronic disease over the life course or the possibility of incident cognitive impairment beyond study year 5. In addition, because individuals with lower literacy may have been more likely to die before the study, or have

considerable impairments at study recruitment, our results may underestimate the association between limited literacy and mortality. Measurement error may have been introduced by the REALM or the 3MS. As the REALM is scored, in part, based on a subject's pronunciation of words, we cannot determine the extent to which regional accents or culture-specific dialects may have contributed to lower scores, independent of literacy skills. Furthermore, the 5-point decline on the 100-point 3MS that defined incident cognitive impairment, while very conservative, may not have captured all subjects with incident cognitive impairment. The external validity of our findings is also limited by the sampling strategy that restricted the sample to well-functioning elders, age 71 to 82 years in 2 US urban areas.

This study demonstrates that, among a diverse cohort of community-dwelling elders, having limited literacy was associated with nearly a 2-fold increase in mortality when compared with having adequate literacy. Limited literacy was also associated with a higher burden of chronic conditions, and poorer self-rated health, access to care, and psychosocial status; yet, the effect of limited literacy on mortality was independent of these variables. As the aging population grows worldwide, as the prevalence of chronic disease increases,[13] and as the effects of socioeconomic disparities on morbidity and mortality persist into older age, the results of this study have relevance to public health on a global scale. Further research is needed to explain the association between limited literacy and mortality and to develop interventions to reduce literacy-associated disparities in health.

This study was supported by the NIH grants NIA N01-AG-6-2101, N01-AG-6-2103, and N01-AG-6-2106. Dr. Sudore was supported by the NIH Research Training in Geriatric Medicine Grant AG000212 and by the Pfizer Fellowship in Clear Health Communication. Dr. Schillinger was supported by an NIH Mentored Clinical Scientist Award K-23 RR16539-03.

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